The unmet needs of partners and caregivers of adults diagnosed with cancer: A systematic review

Lambert, S. D., Harrison, J. D., Smith, E., Bonevski, B., Carey, M., Lawsin, C., Paul, C., & Girgis, A. (2012). The unmet needs of partners and caregivers of adults diagnosed with cancer: A systematic review. *BMJ Supportive and Palliative Care* (impact factor: 2.385), *2*(3), 224-230.

Sylvie D. Lambert, PhD
National Health and Medical Research Council Research Fellow, Translational Cancer Research Unit, Ingham Institute for Applied Medical Research, South Western Sydney Clinical School, Faculty of Medicine, The University of New South Wales, Sydney, Australia

James D. Harrison, PhD
Deputy Director, Surgical Outcomes Research Centre (SOuRCe), Sydney Local Health District & Sydney, School of Public Health, Royal Prince Alfred Hospital, The University of Sydney, Sydney, Australia

Ellen Smith, BPsyc (Hons)
Research Assistant, The University of Newcastle, Newcastle, Australia

Billie Bonevski, PhD
Cancer Institute New South Wales (CINSW) Research Fellow, Priority Research Centre for Health Behaviour, School of Medicine & Public Health, The University of Newcastle & Hunter Medical Research Institute, Newcastle, Australia

Mariko Carey, DPsych
Hunter Medical Research Institute Post-doctoral Research Fellow, Priority Research Centre for Health Behaviour, School of Medicine & Public Health, The University of Newcastle, Newcastle, Australia

Catalina Lawsin, PhD
Lecturer, School of Psychology, The University of Sydney, Sydney, Australia

Chris Paul, PhD
Senior Research Academic , Priority Research Centre for Health Behaviour,
School of Medicine & Public Health, The University of Newcastle,
Newcastle, Australia

Afaf Girgis, PhD, BSc (Hons)
Executive Director, Translational Cancer Research Unit, Ingham Institute for Applied Medical Research, South Western Sydney Clinical School, Faculty of Medicine, The University of New South Wales, Sydney, Australia

Correspondence:
Dr Sylvie Lambert
Ingham Institute for Applied Medical Research, South Western Sydney Clinical School,
Faculty of Medicine, The University of New South Wales
PO Box 3151 (Westfield), Liverpool, NSW 2170
Australia
Tel: +61(2) 9828 4514 Fax: +61(2) 9828 4511

Email #1: sylvie.d.lambert@gmail.com Email #2: s.lambert@unsw.edu.au

Keywords: caregivers, unmet supportive care needs, cancer supportive care, psychosocial oncology, survivors

Word count: 3392

Abstract

Objectives: A partner or caregiver is typically the patient's primary support person and is also deeply affected by the cancer diagnosis. Recognition of the impact of cancer on partners and caregivers has prompted efforts to document their unmet supportive care needs. This review aimed to: 1) quantify the prevalence of unmet needs reported by partners and caregivers, 2) categorise their unmet needs by domain, and 3) identify the main variables associated with reporting more unmet needs.

Methods: Manuscripts were identified through systematically searching electronic databases, perusing reference lists of retrieved publications, online searching of key journals, and contacting researchers in this field.

Results: Unmet need items across 29 manuscripts were clustered into six domains: comprehensive cancer care (prevalence = 1.1% - 96%), emotional and psychological (3% to 93.2%), partner or caregiver impact and daily activities (2.8% - 79%), relationship (3.7% and 58%), information (2.2% – 86%), and spiritual (2% - 43%). Studies of caregivers of palliative care or terminal patients often reported higher prevalence of unmet needs than studies of caregivers of cancer survivors. Variables associated with higher unmet needs included being female, not being the spouse of the patient, having lower social support, or reporting distress.

Conclusions: Despite the ability to classify unmet needs within broad domains, quantification of unmet needs was challenging. This was mainly due to the diversity in methods used across studies (e.g., different measures, variability in conceptualisation of unmet needs). Rigorous, context-specific, longitudinal studies that use validated measures are needed to benefit future intervention research.

INTRODUCTION

Individuals diagnosed with cancer report needs for emotional support, social and spiritual care, advice about managing symptoms and side effects, and high-quality information.(1, 2) These aspects of care are typically classified under the umbrella term - '*supportive cancer care*'. In light of the accumulating evidence reinforcing the value of supportive care in helping patients and partners and caregivers (P&Cs) cope with their needs and in reducing psychological distress,(3) supportive care is recommended for all people with cancer and their P&Cs from the time of diagnosis.(1, 3)

One prerequisite to the co-ordinated delivery of supportive care includes the comprehensive assessment of the extent to which patients' and P&Cs' needs are met.(1) A need is typically labelled as 'unmet' when services required to deal with the particular issue are not received.(4) From a health care delivery perspective, although 'needs' identify problems, 'unmet needs' provide additional information on where support deficiencies lie. This information can then be used to prioritize resources where unmet needs are high.(4) The concept of 'unmet needs' has inherent appeal to policy makers, clinicians, and researchers, reflected by the steady increase in the literature associated with this concept over the past decade.(5, 6)

Whilst much of the focus in supportive cancer care has been on assisting patients, there is growing recognition that P&Cs are susceptible to their own unique needs.(1, 7-9) P&Cs often see themselves as jointly '*fighting the illness*' with patients (10) and face multiple '*ripple effects*' of the diagnosis and treatment.(8, 9, 11-13) For many, coping with cancer challenges can be physically, socially, and psychologically challenging.(7-9, 12, 13) Some of P&Cs' most prominent supportive care needs mirror those identified by patients, and there is increasing evidence that many of these also remain unmet.(14-20) This is concerning, as unmet needs not only compromise P&Cs' quality of life,(14, 21-23) but these also adversely impact on patients' distress.(22) Hence, both patients' and caregivers' illness adjustment may be optimised if P&Cs' unmet needs are addressed.(23) This systematic review aimed to: 1) Quantify the prevalence of unmet needs reported by P&Cs' of adults with cancer; 2) categorise P&Cs' unmet needs by domain; and 3) identify the main variables associated with reporting unmet needs.

METHODS

Methodological framework

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement was used.(24)

Search methods

Papers were primarily identified through a systematic search of the electronic Medline, CINAHL, CANCERLIT, AMED, Embase, and PsycInfo databases. Secondary strategies included 1) perusing the reference lists of manuscripts retrieved; 2) online searching of key journals (*Cancer, Cancer Nursing, Journal of Cancer Survivorship, Journal of Psychosocial Oncology, Oncology Nursing Forum, Patient Education and Counselling, Psycho-Oncology,* and *Supportive Care in Cancer)*; 3) contacting researchers known to conduct work in this area; and 4) using the '*find similar*' function in the databases for seminal manuscripts.

Search terms used

The 'unmet needs' search terms modelled those used by Harrison et al.(6) and included: need* assess*, need* survey, need* instrument, need* question*, unmet need*, health need*, info* need*, physical need*, emot* need*, psycho* need*, support* care need*, perceived need*, OR need satisfaction. The 'partners/caregivers' search terms were similar to those used by Northouse et al.(25): support person, wife, wives, husband(s), close relative(s), next of kin(s), significant other(s), couple(s), partner(s), spouse(s), carer(s), family, families, relative(s), OR caregiver(s). 'Cancer' search terms used were neoplasm, oncology, tumor, OR cancer. The 'unmet needs', 'partners/caregivers', and 'cancer' search terms were then combined using the AND function and the search was limited to "all adults" and 1995 onwards (last review was conducted in 1993(26)). The same search terms were used across the databases; however, if a database specific MeSH relevant term was identified, it was then added. The full electronic search strategy used for one database (PsycInfo) is included in Appendix 1 (web only file).

Inclusion/exclusion criteria

Manuscripts considered for this review were published in a peer-reviewed journal and reported primary data on the unmet supportive care needs of P&Cs of adults with cancer, from diagnosis to palliative care (excluding bereavement phase). Studies published in either English or French were included. Qualitative studies were excluded, as it was often unclear whether a reported need was met or not. Studies of professional or paid carers were also excluded.

Study selection and data extraction

For all databases, two reviewers (SL, ES) independently ran the search terms, screened the titles, read the abstracts, obtained full-texts, and extracted the data using a data collection form based on the Cochrane library's recommendations for data extraction.(27) At each stage of the review process, disagreements were discussed between reviewers. For each manuscript, a third reviewer corroborated the data extracted and its integration in the review. Where results were unclear, authors were contacted for clarification.

Data analysis

Results across studies were pooled and prevalence of unmet needs compiled. When reported, the average number of unmet needs was retained. To facilitate comparison across studies, and where appropriate, averages were standardised from 0 to 100. Most studies reviewed reported on specific unmet need items and to facilitate reporting, comparable need items were combined and clustered in domains. The labelling of these domains was guided by studies identified in this review.(20, 28)

RESULTS

Overview of studies reviewed

The search identified 3,228 potentially relevant titles of which 3,199 were rejected (see Figure 1). Details of the 29 manuscripts retained are shown in Table 1 (web only file). In almost three quarters of the studies, participants were the partner or spouse of the individual diagnosed (16-20, 23, 28-40) and studies typically included a predominance of female P&Cs.(14, 17, 22, 23, 29, 31, 32, 35, 36, 38, 39, 41, 42) When reported, average age of participants ranged from 47 to 61 years (16, 17, 20, 22, 28-31, 33-36, 43-45) and time since diagnosis from two to 71 months.(17, 22, 28-31, 37) Most studies included P&Cs of individuals diagnosed with tumours from a range of sites and/or at various stages along the illness trajectory,(16, 17, 19-23, 28, 29, 31, 35-37, 41, 42, 45) which in turn limited the interpretation of findings along tumour specific variables.

Overall prevalence of unmet needs

The reported mean number of unmet needs ranged between 1.3 and 16 (range measured = 17-67).(14, 17, 18, 22, 30, 35, 41, 45, 46) Standardisation revealed that, on average, 5% - 47% of needs remained unmet, with several studies finding that up to 10% of assessed needs were unmet.(17, 18, 22, 30, 35) Higher levels of unmet needs were experienced by P&Cs of individuals diagnosed with a brain tumour (14) or those in the palliative care phase.(46)

Eight studies reported between 15.5% - 67.9% (17, 19, 22, 23, 28, 30, 31, 35) of P&Cs experienced at least one unmet need. Kim et al.(23) reported the upper limit of 67.9% among P&Cs of individuals with colorectal cancer two months post-diagnosis. In this study, overall prevalence of reporting unmet needs was found to decrease as time since diagnosis increased. Other studies used a higher cut-off for their reporting. For instance, Soothill et al.(19) found 28% of P&Cs identified *three or more significant* unmet needs. Similarly, Girgis et al.(17) found that 36% of P&Cs reported *three or more* unmet needs at 6 months post-diagnosis, with a significant decrease to 17.5% at 24 months.(17) Ten or more unmet needs were reported by 17% of P&Cs in a study by Hodgkinson et al.(28) and by 10% of P&Cs in the Hwang et al.(32) study.

[insert figure 1 here]

Prevalence of unmet needs by domain

Comprehensive cancer care unmet needs

The prevalence of unmet comprehensive cancer care needs ranged from 1.1% to 96% across 22 studies with almost half reporting that up to a fifth of P&Cs report an unmet need in this domain.(17, 19, 20, 22, 23, 29-32) Seven categories of unmet needs were identified and are shown in Table 2. Fewer P&Cs of people with head and neck cancer (29) or cancer survivors (17) identified needing help with these needs. Comprehensive cancer care needs were also mostly met in the Soothill et al.(19, 20) studies among a mixed group of patients. Conversely, higher prevalence of unmet needs were found in studies among P&Cs of patients hospitalized,(38) in the acute diagnostic and treatment phases,(33, 40) or in the palliative care phase.(36, 41, 46, 47)

Emotional and psychological unmet needs

Prevalence of emotional and psychological unmet needs ranged from 3% to 93.2% across 15 studies with most of these identifying that up to a third of P&Cs endorsed a given psychological unmet need item.(16, 17, 19, 20, 22, 23, 28, 30, 31) Emotional and psychological unmet needs across studies are represented by five categories shown in Table 2. Across most of these unmet needs categories, lower prevalence was reported by P&Cs of cancer survivors.(17, 22, 28) Needs related to dealing with negative feelings and getting emotional support for self remained largely unmet for P&Cs of individuals in the palliative care phase.(46) A high prevalence of unmet needs related to helping P&Cs provide emotional support to patients was reported among wives of men with prostate cancer (53% - 59%) in the acute phases of the illness (33, 40) and among a mixed group of P&Cs (50.7%).(37) Of note, in the study by Kim et al.(23) across all three cohorts (2-60 months post-diagnosis), psychological unmet needs were most prevalent.

Partner or caregiver impact and daily activities unmet needs

Across 22 studies, between 2.8% and 79% of P&Cs reported unmet partner or caregiver impact and/or daily activities needs. Half of these found that up to approximately a third of P&Cs identified unmet needs in this domain.(16, 17, 19, 20, 22, 23, 28-32) Common categories of unmet needs in this domain are listed in Table 2. Overall, lower prevalence of unmet needs were reported in studies involving P&Cs of cancer survivors.(17, 22, 23, 28) A higher proportion of P&Cs of individuals in the palliative care phase endorsed unmet needs in this domain.(36, 46)

Relationship unmet needs

Eleven studies found that between 3.7% and 58% of P&Cs reported unmet needs related to their relationships or interactions with the patient or others. Most studies found that up to a quarter of P&Cs reported relationship unmet needs.(17, 22, 23, 28, 30, 31) The most prominent areas of relationship unmet needs are shown in Table 2. Overall, the pattern of prevalence was consistent with the other domains, where studies of P&Cs of cancer survivors reported lower unmet needs(17, 22, 28, 30) than P&Cs in the palliative care phase.(46)

Information unmet needs

Twenty studies found 2.2% – 86% of P&Cs experienced unmet information needs with almost half of these reporting that an unmet information need was reported by up to a third of P&Cs (Table 2).(14, 16, 17, 19, 20, 23, 29, 32) . Illness and medical unmet information needs were notably lower in studies that involved P&Cs of cancer survivors.(17, 29) A high prevalence of information unmet needs were found among P&Cs in the early (37, 40) or palliative phase.(46)

Spirituality unmet needs

Spirituality needs were less often documented (2% - 43%), but a common unmet need related to feeling there is hope for the future (Table 2). Typically, studies identified spiritual needs remained unmet for less than 20% of P&Cs.(19, 20, 22, 28, 29, 32, 33, 40)

Table 2. Summary of domains and prevalence range for sub-categories of unmet needs

Domains and sub-categories of unmet needs	**Prevalence range**
Comprehensive cancer care	
be told about the help health care professionals can offer	**12.4% - 77%** (20, 29, 32, 33, 36, 38, 40, 41, 47)
have a supportive relationship with health care professionals	**4.5% - 96%** (16, 17, 19, 20, 23, 29, 32, 33, 36, 38, 40, 41, 47)
access to health services	**10% - 65%** (16-20, 22, 28, 30, 31, 36, 45, 46)
have possibilities to participate or help in patient's care	**1.1% - 86%** (14, 16, 17, 19, 20, 22, 23, 28-30, 32, 33, 36-38, 40, 41, 47)
information provided by health care professionals was appropriate	**1.1% - 51%** (17, 19, 20, 22, 28-30, 32, 33, 36, 40, 41, 47)
obtain the best possible care for patient	**2.2% - 42.4%** (14, 17, 22, 23, 28-30, 32, 33, 40, 41, 46, 47)
co-ordination and continuity of care	**5.3% - 22%** (17, 18, 22, 28, 30, 31)
Emotional and psychological	
help dealing with own emotional distress (e.g., anger, guilt, sadness, anxiety, depression)	**5.8% - 93.2%** (16, 17, 19, 20, 23, 46)
get emotional support for self/have someone to talk to	**3% - 83.1%** (17, 19, 20, 22, 28, 30, 31, 46)
know how to provide emotional support to patient or others	**3.4% - 59%** (14, 16, 17, 19, 20, 22, 23, 28, 30, 31, 33, 37, 40, 45)
manage fears about the situation getting worse	**5.5% - 51.2%** (14, 16, 17, 22, 28, 30, 31, 45)
find meaning (self or partner)	**4.6% - 24.3%** (19, 20, 23)
Partner or caregiver impact and daily activities	
financial support, including life and/or travel insurance	**4.7% - 79%** (17, 22, 28, 30, 31, 36, 46)
know how to maintain sense of control	**24% - 66.1%** (19, 20, 46)
deal with uncertainty and life after cancer	**3.4% - 44.1%** (14, 16, 17, 19, 20, 22, 28, 30, 31, 45, 46)
curtail impact on lifestyle and schedule	**4.6% - 59.3%** (16, 19, 20, 23, 46)
deal with impact on work	**2.8% – 39.1%** (14, 17, 23, 28, 45)
help looking after own health	**4.5% - 54%** (14, 17, 19, 20, 28, 29, 32, 33, 40, 41, 46, 47)
assistance with patient daily needs (e.g., preparing meals, transportation, hygiene) and illness management tasks	**3.1% - 42.8%** (18-23, 28, 30, 37, 46)
balance own needs with caregiving	**7.6% - 34.8%** (14, 17, 23)
support dealing with changes in identity	**26% - 32%** (19, 20)
help from others to manage caregiving roles	**3.6% - 37.3%** (19, 20, 23, 28, 30, 46)

Domains and sub-categories of unmet needs	**Prevalence range**
Relationship	
help communicating with patient about illness and his/her concerns	**7% - 47%** (23, 33, 40, 46)
have an intimate relationship with the patient and consideration for sexual need	**7.2% - 58%** (17, 19, 20, 22, 23, 28, 30, 33, 40)
help communicating with others (e.g., family, friends)	**4% -43.1%** (22, 28, 33, 40, 46)
have a satisfactory relationships with others	**5.4% - 25.2%** (17, 22, 23, 28, 30, 31)
deal with changes in relationship with partner	**3.7% - 23.2%** (17, 22, 23, 28, 30, 31)
Information	
knowing what to expect	**12.4% - 76.6%** (19, 20, 29, 32, 33, 37, 40, 41, 46, 47)
the illness and treatment (e.g., diagnosis, prognosis, treatment)	**2.2% - 86%** (14, 16, 17, 19, 20, 23, 29, 32, 33, 36-38, 40, 41, 45-47)
death and dying	**11.9% - 67.8%** (36, 46)
providing care to patient	**2.3% - 62%** (16, 17, 19, 20, 28-33, 37, 40, 41, 45-47)
Spirituality	
Feel there is hope for the future	**6.7% - 43%** (18-20, 29, 32, 33, 40, 41, 47)
Receive spiritual support	2% - 11% (19, 20, 22, 28)

Variables associated with partners' and caregivers' unmet needs

Relationships between level of unmet needs and: demographics, psychosocial variables, illness variables and/or health care context are summarised in Table 3.

Caregiver demographics

Overall, findings of the impact of P&Cs' demographic characteristics on unmet needs remain equivocal. In several studies, age,(19, 22, 30, 31, 33, 37, 44) sex,(19, 37, 45) education,(33, 37, 40) and employment (19, 23, 30, 37, 44, 45) were not significantly associated with unmet needs. When a significant relationship was reported, the direction of that relationship varied across studies (see Table 3).(23, 28, 36, 38, 40, 41, 43-45) Of note, five studies reported that caregivers who are not the patient's partner experienced higher unmet needs than those that were the partner.(19, 36, 38, 41, 47)

Patient or caregiver psychosocial variables

The relationships between elevated partner or caregiver distress,(22, 45) anxiety,(14, 17, 28, 30, 31, 35, 46) and/or depression (14, 17, 28, 30, 35, 46) and higher unmet needs were confirmed across several studies (see Table 3). Two studies found a positive association between patients' and P&Cs' unmet needs.(22, 31) Additional variables associated with higher unmet needs included low social support,(17, 19) low relationship satisfaction,(22) and having caring responsibilities.(17, 19, 32, 46) Of note, Kim et al.(23) and Girgis et al.(17) found the associations between psychosocial variables and unmet needs to vary across time.

Caregiver or patient health/illness variables

Numerous studies did not support a significant relationship between caregiver or patient health/illness variables and unmet needs (Table 3).(14, 19, 22, 28, 30, 31, 37, 45) A few studies have suggested higher unmet needs among P&Cs of individuals with advanced cancer.(17, 19, 34, 41)

Health care context and care variables

Several studies have suggested a relationship between some cancer care variables and unmet needs (Table 3).(21, 32, 34, 47) Examples include specialised versus acute cancer care units (21, 47) and source of caregiver information.(34)

Table 3. Summary of findings of common variables examined for their association with unmet needs

Studies	**Demographics**					**Psychosocial**						**Illness**				**Health care context**	
	Older	Women	High Education	Employed	Not the spouse/ not living with patient	Low social support/ relationship satisfaction	Other caring responsebilities or burden	Caregiver distress, anxiety or depression	Patient distress, anxiety or depression	QOL	Patients' unmet needs	Tumour type	Time since diagnosis or treatment	Stage of disease	Treatment	Care setting	Insurance
Buck & McMillan (35)								↑	↑								
Buscemi et al. (46)							↑	↑									
Chambers et al. (45)	↓	↔	↑	↔	↔			↑							↔		
Eriksson & Lauri (38)		↑	↓		↑												
Eriksson et al. (36)	patient ↑			↓	↑								↑				
Fridriksdottir et al. (47)					↑											Palliative care ↓	
Fridriksdottir et al. (41)	↓	↑		↑	↑									↑		↔	
Girgis et al. (17)						↑	↑	↑		Physical ↓		6 + 24 months lung ↑					
Hodgkinson et al. (22)	↔					↑		↑	↑	Mental ↓ Physical ↔	↑	↔	↔	↔			
Hodgkinson et al. (28)	↓							↑		Physical ↔ Mental ↓			↔				
Hwang et al. (32)							↑				Perception of patient's unmet needs ↑					Satisfaction with care ↓	
Iconomou et al. (37)	↔	↔	↔	↔	↔							↔	↔		↔		

Studies	**Demographics**					**Psychosocial**						**Illness**				**Health care context**	
	Older	Women	High Education	Employed	Not the spouse/ not living with patient	Low social support/ relationship satisfaction	Other caring responsebilities or burden	Caregiver distress, anxiety or depression	Patient distress, anxiety or depression	QOL	Patients’ unmet needs	Tumour type	Time since diagnosis or treatment	Stage of disease	Treatment	Care setting	Insurance
Janda et al. (14)								↑				⇔			⇔		
Kilpatrick et al. (43)			↓														
Kim et al. (23)	** ↑↓	↑	↑ *	⇔													
Mason (40)	↑		⇔														
Mason (33)	⇔		⇔														
Molassiotis et al. (31)	⇔							↑	↑		↑		⇔		⇔		
Nikoletti et al. (34)														↑		Nurse/ medical staff source of information ↓	Private insurance ↑
Park et al. (21)																Hospice care ↓	
Ross et al. (29)										⇔							
Salminen et al. (44)	⇔		↑	⇔													
Soothill et al. (19)	⇔	⇔		⇔	↑	↑	↑			↑		⇔		Palliative ↑			
Stafford et al. (30)	⇔			⇔				↑				⇔		⇔			

*- at 2 years and only for the psychosocial unmet needs. ** - relationship varied across cohorts. ⇔= no significant relationship, ↑= positive, significant relationship, ↓ = negative, significant relationship, empty cell = variable not tested.

DISCUSSION

This systematic review summarised P&Cs’ unmet needs across 29 studies and identified a sub-group of P&Cs at risk of reporting more unmet needs than their peers.

Prevalence of unmet needs – Is experiencing one unmet need significant?

A popular indicator to gauge the overall prevalence of unmet needs was the proportion of P&Cs reporting at least one unmet need.(17, 19, 22, 23, 28, 30, 31, 35) It is difficult to determine the significance of experiencing one unmet need, particularly as to date there has been no attempt at quantifying the clinical significance of a given unmet need.(48) However, as many of the top ranking unmet needs across studies pertained to coping with psychological or emotional distress,(16, 17, 19, 20, 23, 46) it is foreseeable that experiencing any of these, even if just one, could adversely impact clinical outcomes.

Unmet needs domains

Across the six unmet needs domains identified, it appeared that an unmet need item is typically endorsed by up to a third of P&Cs with a higher proportion of P&Cs of individuals in the palliative care phases reporting unmet needs.(36, 41, 46, 47) Fewer P&Css of cancer survivors identified unmet needs,(17, 22, 23, 28) a finding consist with the Harrison et al.(6) review of patients’ needs. Unmet needs in the comprehensive cancer domain reflected P&Cs’ need to be aware of the resources available to them, have a sympathetic relationship with health care professionals, and be considered an integral part of the health team. Studies of emotional and psychological unmet needs highlighted P&Cs’ need for assistance to manage their distress or negative feelings and reduce stress in the patient’s life. Interestingly, in a recent study by Deshield et al.,(49) 80% of caregivers reported they helped patients deal with their emotions and about a third reported this to the most difficult aspect of caregiving. Issues of curtailing impact of caregiving on lifestyle and schedule and performing illness management tasks were raised within the partner or caregiver impact and daily activities domain. In the relationship domain, communicating with the patient and sexuality and intimacy were prominent unmet needs. Several studies found many P&Cs do not get the information they needed, including information about what to expect and the illness and treatment. Overall, spirituality needs were assessed in fewer studies; however, when these were examined, ‘*feeling hope for the future*’ was a prominent unmet need.

Partners and caregivers at risk of experiencing unmet needs

As indicated in Table 3, the sub-group of P&Cs at risk of experiencing more unmet needs included those who were female, were not the spouse nor living with the patient, had lower social support, and reported distress, anxiety and/or depression. Findings on gender and social support mirror those of studies on predictors of P&Cs’ anxiety and depression.(12, 13, 50, 51) Of note, many of the studies reviewed corroborated that illness variables were not associated with level of unmet needs. However, these conclusions should be interpreted with caution, as many of these variables were reported in mostly cross-sectional studies. Hence, causality or lack thereof cannot be inferred from these data.

Implications for service delivery

The key categories of unmet needs identified in this review provide an evidence base to guide the design and implementation of supportive care services, particularly towards those unmet needs that are amenable to change and vulnerable partner/caregiver sub-groups. For instance, top ranking psychological unmet needs across a number of studies included helping P&Cs’ manage their own emotional distress as well as the patients’ distress, which in turn suggests the need for coping skills training interventions.

In addition, the findings of this review emphasised that a multidisciplinary approach to supportive care for P&Cs is needed. Although the concept of multidisciplinary care is well-recognised for oncology patients, it is questionable whether this model of care has reached P&Cs in the same way.(19)

However, beyond the issues of resource allocation, P&Cs often do not access services, even when these are available.(52) Hence, this suggests that health care professionals might first have to reassure P&Cs that the support they provide patients is considerable and their own needs are legitimate.

Methodological issues of studies reviewed

Response rates were not consistently reported and when they were, these were often low. Many authors acknowledged that clinicians hesitated to refer P&Cs of acutely ill patients; this selection bias might have led to underestimating unmet needs. In addition, there is an under-inclusion of individuals from culturally and linguistically diverse (CALD) backgrounds. As few longitudinal studies were found,(17) little is still known about how unmet needs change over time. Furthermore, studies gave little consideration to the location of treatment or availability of supportive care services, which in turn might have influenced the prevalence of unmet needs reported.

One of the main challenges of this review was the quantification of unmet needs to obtain a useful depiction of P&Cs’ experiences, a challenge also raised by Harrison et al.,(6) and can be attributed to the: 1) wide variety of unmet needs measures used and 2) differences in the definition and analysis of unmet needs. For some studies a need was labelled unmet only if it was *both* important *and* not satisfied. Even when comparable measures were used, some studies considered ‘moderate or high’ unmet needs,(17) where others accounted for ‘low, moderate or high’ ones.(28) In addition, the timing of assessments varied dramatically and for some measures, items were confusing and elusive for reviewers, which raises concerns about how these were interpreted by P&Cs.

Future research implications

Longitudinal studies recruiting P&Cs in the early post-diagnosis phase to map their unmet needs as they confront different milestones along the illness trajectory are required. Moreover, studies among non-spouse, younger, and/or CALD caregivers are also needed. Another research area under explored is the influence of the availability of supportive care services on unmet needs. Furthermore, unmet needs measures require further analysis, including whether items are comprehensive and understood by P&Cs in the intended manner. Although a number of short measures are available to screen for patients' unmet needs (e.g. SCNS-ST9),(53) most caregiver measures included more than 30 items and comparable brief measures to facilitate integration in clinical practice are needed. This review also highlighted a demand for the development and evaluation of multidisciplinary interventions that could include *both* patients *and* their P&Cs, given the overlap and interdependence in unmet needs.

Limitations of the review

It is possible that some eligible papers were missed, as papers published in languages other than English or French and those that were not published in peer-reviewed journals were not included. Although our review was from 1995 and there is a 2-year gap between the 1993 review by Laizner (26) and this one, it is unlikely that publications have been missed since most studies retrieved were published after 2000.

CONCLUSIONS

This systematic review identified 29 studies that quantified P&Cs' unmet needs. Prevalence of unmet needs across six domains varied greatly (range 1% - 96%) and was particularly notable among P&Cs of individuals in the palliative care phase. Furthermore, caregivers who were female, not the spouse nor living with the patient, had lower social support, or reported higher distress seemed more at risk. Overall, findings can be used to provide an evidence base for decision-making regarding allocation of health care resources towards those sub-groups more at risk of experiencing unmet needs and the content of psychosocial interventions to target those key areas of unmet needs.

Figure caption:
Figure 1. PRISMA flow diagram of search process

Acknowledgements: Dr Sylvie Lambert is supported by a National Health and Medical Research Council Training Fellowship, Dr Mariko Carey by a Hunter Medical Research Institute Post-doctoral Fellowship, Dr Billie Bonevski by a Cancer Institute New South Wales Career Development Fellowship and Prof Afaf Girgis by a Cancer Institute New South Wales grant.

Competing Interest: None declared

References

1 National Institute of Clinical Excellence (NICE). Guidance on cancer services: Improving supportive and palliative care for adults with cancer. London: National Institute of Clinical Excellence (NICE) 2004.

2 Lambert SD, Loiselle CG, Macdonald ME. An in-depth exploration of information-seeking behavior among individuals with cancer: Part 1 Understanding differential patterns of active information-seeking. *Cancer Nurs* 2009;**32**:11-23.

3 National Breast Cancer Centre NCCI. Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer. Camperdown, NSW: National Breast Cancer Centre 2003.

4 Sanson-Fisher R, Girgis A, Boyes A, et al. The unmet supportive care needs of patients with cancer. *Cancer* 2000;**88**:226-37.

5 Carey M, Lambert S, Smits R, et al. The unfulfilled promise: A systematic review of interventions to reduce the unmet supportive care needs of cancer patients. *Support Care in Cancer* 2012;**20**:207-19.

6 Harrison J, Young J, Price M, et al. What are the unmet supportive care needs of people with cancer? A systematic review. *Support Care in Cancer* 2009;**17**:1117-28.

7 Girgis A, Lambert SD. Caregivers of cancer survivors: The state of the field. *Cancer Forum* 2009;**33**:167-71.

8 Lewis FM. The family's "stuck points" in adjusting to cancer. In: Holland JC, Breitbart WS, Jacobsen PB, Lederberg MS, Loscalzo MJ, McCorkle R, eds. Psycho-Oncology. 2nd ed. New York, NY: Oxford University Press 2010:511-515.

9 Girgis A, Lambert SD, Johnson C, et al. Is anyone caring for the caregivers? The physical, psychosocial, relationship and economic burden of caring for people with cancer. *J Oncol Pract* In press.

10 Thomas C, Morris S, Soothill K, et al. What are the psychosocial needs of cancer patients and their main carers? The Institute for Health Research, Lancaster University. http://www.lancs.ac.uk/fass/apsocsci/cancer/complete (accessed March 10, 2009).

11 Given B, Sherwood P, Given C. Family Care During Cancer Care. In: Miller S, Bowen D, Croyle RT, Rowland JH, ed. Handbook of Cancer Control and Behavioral Science: A Resource for researchers, Practitioners, and Policymakers. Washington, DC: American Psychological Association 2009:391-408.

12 Lambert S, Girgis A, Lecathelinais C, Stacey F. Walking a mile in their shoes: Anxiety and depression among caregivers of cancer survivors at six and 12 months post-diagnosis. *Support Care Cancer.* Accepted.

13 Lambert SD, Jones B, Girgis A, Lecathelinais C. Distressed partners and caregivers do not recover easily: Adjustment trajectories among partners and caregivers of cancer survivors. *Annals of Behavioral Medicine*. Accepted.

14 Janda M, Steginga S, Dunn J, et al. Unmet supportive care needs and interest in services among patients with a brain tumour and their carers. *Patient Educ Couns* 2008;**71**:251-8.

15 Grimm PM, Zawacki KL, Mock V, et al. Caregiver responses and needs. *Cancer Practice* 2000;**8**:120-8.

16 Clavarino AM, Lowe JB, Carmont SA, et al. The needs of cancer patients and their families from rural and remote areas of Queensland. *Aust J Rural Health* 2002;**10**:188-95.

17 Girgis A, Lambert SD, McElduff P, et al. Some things change, some things stay the same: A longitudinal analysis of cancer caregivers' unmet supportive care needs. *Psychooncology* 2011; Accepted with minor revisions.

18 Osse BH, Vernooij-Dassen MJ, Schade E, et al. Problems experienced by the informal caregivers of cancer patients and their needs for support. *Cancer Nur* 2006;**29**:378-88.

19 Soothill K, Morris SM, Harman JC, et al. Informal carers of cancer patients: What are their unmet psychosocial needs? *Health Soc Care Community* 2001;**9**:464-75.

20 Soothill K, Morris SM, Thomas C, et al. The universal, situational, and personal needs of cancer patients and their main carers. *Eur J Oncol Nurs* 2003;**7**:5-13.

21 Park SM, Kim YJ, Kim S, et al. Impact of caregivers' unmet needs for supportive care on quality of terminal cancer care delivered and caregiver's workforce performance. *Support Care Cancer* 2010;**18**:699-706.

22 Hodgkinson K, Butow P, Hunt G, et al. Life after cancer: Couples’ and partners’ psychological adjustment and supportive care needs. S*upport Care Cancer* 2007;**15**:405-15.

23 Kim Y, Kashy DA, Spillers RL, et al. Needs assessment of family caregivers of cancer survivors: Three cohorts comparison. *Psychooncology* 2010;**19**:573-82.

24 Moher D, Liberati A, Tetzlaff J, et al. Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *Annals of Internal Medicine* 2009;**151**:264-69.

25 Northouse LL, Katapodi MC, Song L, et al. Interventions with family caregivers of cancer patients: Meta-analysis of randomized trials. *CA Cancer J Clin* 2010;**60**:317-39.

26 Laizner AM, Yost LM, Barg FK, et al. Needs of family caregivers of persons with cancer: A review. *Semin Oncol Nurs* 1993;**9**:114-20.

27 Higgins J, Green S. Cochrane Handbook for Systematic Reviews of Interventions Version 5.0.2 [updated September 2009]: The Cochrane Collaboration 2009.

28 Hodgkinson K, Butow P, Hobbs KM, et al. Assessing unmet supportive care needs in partners of cancer survivors: The development and evaluation of the Cancer Survivors' Partners Unmet Needs measure (CaSPUN). *Psychooncology* 2007;**16**:805-13.

29 Ross S, Mosher CE, Ronis-Tobin V, et al. Psychosocial adjustment of family caregivers of head and neck cancer survivors. *Support Care Cancer* 2010;**18**:171-78.

30 Stafford L, Judd F, Stafford L, et al. Partners of long-term gynaecologic cancer survivors: psychiatric morbidity, psychosexual outcomes and supportive care needs. *Gynecol Oncol* 2010;**118**:268-73.

31 Molassiotis A, Wilson B, Blair S, et al. Unmet supportive care needs, psychological well-being and quality of life in patients living with multiple myeloma and their partners. *Psychooncology*. 2010;**20**:88-97.

32 Hwang SS, Chang VT, Alejandro Y, et al. Caregiver unmet needs, burden, and satisfaction in symptomatic advanced cancer patients at a Veterans Affairs (VA) medical center. *Palliative & Supportive Care* 2003;**1**:319-29.

33 Mason TM. Wives of men with prostate cancer postbrachytherapy: Perceived Information Needs and Degree of Being Met. *Cancer Nurs* 2008;**31**(1):32-37.

34 Nikoletti S, Kristjanson LJ, Tataryn D, et al. Information needs and coping styles of primary family caregivers of women following breast cancer surgery. *Oncol Nurs Forum* 2003;**30**:987-96.

35 Buck HG, McMillan SG. The unmet spiritual needs of caregivers of patients with advanced cancer. *Journal of Hospice & Palliative Nursing* 2008;**10**:91-99.

36 Eriksson E, Arve S, Lauri S. Informational and emotional support received by relatives before and after the cancer patient's death. *Eur J Oncol Nurs* 2006;**10**:48-58.

37 Iconomou G, Vagenakis AG, Kalofonos HP. The informational needs, satisfaction with communication, and psychological status of primary caregivers of cancer patients receiving chemotherapy. *Support Care Cancer* 2001;**9**:591-96.

38 Eriksson E, Lauri S. Informational and emotional support for cancer patients' relatives. *Eur J Cancer Care* 2000;**9**:8-15.

39 Andreassen S, Randers I, Naslund E, et al. Information needs following a diagnosis of oesophageal cancer; self-perceived information needs of patients and family members compared with the perceptions of healthcare professionals: A pilot study. *Eur J Cancer Care* 2007;**16**:277-85.

40 Mason TM. Information needs of wives of men following prostatectomy. *Oncol Nurs Forum* 2005;**32**:557-63.

41 Fridriksdottir N, Sigurdardottir, Halfdánardóttir S, et al. Family members of cancer patients: needs, quality of life and symptoms of anxiety and depression. *Acta Oncol* 2011;**50**:252-58.

42 Campbell S, Sanson-Fisher R, Taylor-Brown J, et al. The Cancer Support Person's Unmet Needs Survey. *Cancer* 2009;**115**:3351-59.

43 Kilpatrick MG, Kristjanson LJ, Tataryn DJ, et al. Information needs of husbands of women with breast cancer. *Oncol Nurs Forum* 1998;**25**:1595-601.

44 Salminen E, Vire J, Poussa T, et al. Unmet needs in information flow between breast cancer patients, their spouses, and physicians. *Suppor Care Cancer* 2004;**12**:663-68.

45 Chambers SK, Girgis A, Occhipinti S, et al. Psychological distress and unmet supportive care needs in cancer patients and carers who contact cancer helplines. *European Journal of Cancer Care* 2011;**21**:213-23.

46 Buscemi V, Font A, Viladricht C. Focus on relationship between the caregivers unmet needs and other caregiving outcomes in cancer palliative care. *Psicooncologia* 2010;**7**:109-25.

47 Fridriksdottir N, Sigurdardottir V, Gunnarsdottir S. Important needs of families in acute and palliative care settings assessed with the Family Inventory of Needs. *Palliat Med* 2006;**20**:425-32.

48 Sanson-Fisher R, Carey M, Paul C. Measuring the unmet needs of those with cancer: A critical overview. *Cancer Forum* 2009;**33**:198-201.

49 Deshields TL, Rihanek A, Potter P, et al. Psychosocial aspects of caregiving: perceptions of cancer patients and family caregivers. *Support Care Cancer* 2012;**20**:349-56.

50 Hagedoom M, Sanderman R, Bolks H, et al. Distress in couples coping with cancer: a meta-analysis and critical review of role and gender effects. *Psychological Bulletin* 2008;**134**:1-30.

51 Bigatti SM, Wagner CD, Lydon-Lam JR, et al. Depression in husbands of breast cancer patients: relationships to coping and social support. *Support Care Cancer* 2011;**19**:455-66.

52 Vanderwerker L, Laff R, Kadan-Lottick N, et al. Psychiatric Disorders and mental health service use among caregivers of advanced cancer patients. *J Clin Oncol* 2005;**23**:6899-907.

53 Girgis A, Stojanovski E, Boyes A, et al. The next generation of the supportive care needs survey: a brief screening tool for administration in the clinical oncology setting. *Psychooncology* Published online first: Apr 12 2011. DOI: 10.1002/pon.1973.